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“It’s like a problem that doesn’t exist”: The emotional well-being of mothers caring for a child with brain injury.

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“It’s like a problem that doesn’t exist”: The emotional well-being of mothers caring for a child with brain injury.

Abstract

Background: While research has shown that significant burden and adverse psychological impact are associated with caring for a child with brain injury, limited knowledge exists concerning the qualitative experience and impact of this burden.

Primary objective: To provide an account of the experiences of mothers who care for a childhood survivor of brain injury.

Research design: A qualitative, postal survey design.

Methods and procedures: A questionnaire was sent to a convenience sample of mothers (n = 86) of children (aged 8-28 at time of survey). with acquired brain injury, registered with a UK children’s brain injury charity. Five essay style questions enabled mothers to reflect on and describe at length their caring experiences, with particular emphasis being placed on the perceived impact on emotional well-being.

Main outcomes and results: Thematic analysis identified five key themes: Perpetually Anxious, The Guilty Carer, The Labour of Caring, A Self-Conscious Apologist and Perpetually Grieving. Collectively, these themes highlight two core processes shaping mothers’ caring experiences and concomitant mental well-being. Firstly, the collective and enduring nature of caregiver burden over time. Secondly, the crucial role played by socio-cultural values in perpetuating caregiver burden.

Conclusions: Societal norms, based on expectations of the ‘caring role’, serve to marginalise mothers and increase feelings of isolation. Study findings suggest the value of peer support programs as an effective means of providing appropriate social support.

Keywords: mothers, children, brain injury, mental health, emotional well-being, carers, caring experiences, qualitative.

Introduction

The World Health Organization ¹ acknowledges that childhood head injury is a major public health issue worldwide. Over 600,000 children and adolescents under the age of 21 years sustain a traumatic brain injury (TBI) in the USA each year ². In the UK, an estimated 200,000 children acquire a brain injury annually ³. Approximately 4,000 children (0-14 years) are admitted to Australian hospitals every year with a TBI associated diagnosis ⁴. Potential under-estimation in these figures is highlighted by McKinlay, Grace, Horwood, Fergusson, Ridder, and MacFarlane ⁵, who used a birth cohort to estimate the average incidence of youth TBI (aged 0-25 years) at 1750 per 100,000, with only 30% of injuries being admitted to hospital.

Brain injury in children can lead to wide-ranging and persistent cognitive and neuro-behavioural deficits leading to intellectual, personality, mental health and social problems ⁶⁻¹⁰. Rehabilitation may be ongoing for the rest of their lives, with family, particularly parents, often assuming major responsibility for ongoing care and support. With advances in treatment, more children with brain injury are surviving into adulthood so that caregivers are assuming prolonged responsibility

¹¹. An extensive research literature has highlighted the burden caregivers face in providing care, compounded by a lack of formal and informal support ¹²⁻¹⁶.

Given this burden, the adverse impact of caring has been widely identified, with outcomes such as family tension, conflict and sometimes breakdown, financial insecurity, problems in role adjustment and social isolation all reported ^{15, 17-20}. Unsurprisingly, given the circumstances of caring, psychological distress has also been documented ²¹⁻²⁵.

Collectively, such evidence has been important in demonstrating the multiple challenges, associated burden and adverse psychological outcomes experienced by caregivers. A number of limitations are, however, apparent. First, given that the vast majority of studies have used quantitative measurement, caregivers have rarely been given the opportunity to provide extended descriptions of their experiences, such that a more nuanced understanding might be obtained. Second, although the over-representation of women in primary care giving roles has been acknowledged ²⁶, the particularities of the impact of caring for a child with brain injuries on mothers have rarely been explored ²⁷. Third, the overwhelming majority of studies into caregivers' experiences have been undertaken in the United States (US) ¹⁹. Consequently, it is difficult to know the extent to which their findings are relevant to other ABI healthcare and wider social and cultural contexts. Finally, although the emotional and mental health outcomes of caring have been reported, there has been an almost total dearth of research capable of 'unpacking' the processes through which these outcomes come about. In this regard, a need to know much more about the *collective* range of issues caregivers face within particular social settings and concomitant cultural values has been highlighted ²⁸.

This UK study sought to overcome the gaps in knowledge identified above. Accordingly, we explored the nature and impact of caring for a child with brain injury through the adoption of a modified qualitative design. In so doing, we focused, intentionally, on enabling mothers to express the full range of issues they associated with caring for their child.

Methodology

Design

A qualitative postal survey, employing thematic analysis, was used to explore the narratives of mothers of children with ABI. This anonymous questionnaire (as opposed to, for example, face-to-face interviews) was chosen to maximize the opportunity for participants to express their perspectives in a non-threatening environment ²⁹. The questionnaire differed from those typically used in that it adopted an essentially qualitative design by including five essay style questions (see table 1). The opportunities afforded by using a ‘qualitative questionnaire’ ³⁰ of this nature are well established (see, for example, Frith & Gleeson ³¹).

Participants

The questionnaire was distributed to a convenience sample of clients of a UK children’s brain injury charity, comprising mothers (n=86) of children (aged 8-28) with ABI, who had previously indicated their agreement to participate in the research. The mothers had a mean age of 44.77 years and ranged in age from 29-63 years. Their children were aged between 2-28 years with a mean time since injury of approximately 7 years. It was not possible to access hospital records,

and so reports of injury severity came from our participants. See table 1 for additional demographic information on the mothers and their children.

Table 1: Demographic information (mothers and children) and clinical details (children)

Mothers' age:	Range = 29-63 Mean = 44.77 SD = 6.97
Child age:	Range = 2-28 years Mean = 14.95 years SD = 5.44 years
Child gender:	Male - 51 Female - 31 Missing data – 4
Severity of brain injury:	Mild - 7 Moderate - 16 Severe - 45 Missing data - 18
Cause of brain injury:	Road traffic accident - 23 Falls - 20 Bacterial or viral infection - 15 Complications at birth - 5 Tumour - 3 Stroke - 3 Blunt trauma - 3 Other - 7 Missing data - 7
Time since injury:	Range = 6 - 225 months Mean = 83.79 months (6.98 years) SD = 51.15 months

Materials

The questionnaire included the demographic questions, presented in table 2, in addition to the essay style questions. These were designed to enable participants to describe at length, and in whatever ways they considered appropriate, the issues and challenges they associated with caring for their brain injured child. The themes for the questions were developed through a review of the literature with a focus on the emotional well-being of carers. These themes included 'living with brain injury', 'mental health', 'support', 'the future' and 'the experience of caring'. Table 1 presents the questions in full.

Table 2: The five essay style questions

Q1: Thinking about the day-to-day issues which you face caring for your child, can you tell us which you find to be the most challenging and why?
Q2: Thinking about how caring for your child has affected your mental health, can you tell us what you think the main impact has been?
Q3: Are there any types of support which you find particularly helpful in terms of helping you to cope with caring for your child? What is it about these types of support which you find helpful?
Q4: When you think about the future for you and your child, how do you feel? Irrespective of how positive or negative you feel about the future, can you think of anything which would help you face this future more positively?
Q5: Finally, is there anything else you would like to say about your experiences of caring for your child, particularly in relation to your mental health?

Procedure

A letter of invitation was sent to mothers of children who attended a UK based brain injury charity. This letter explained the purpose of the study and what their participation would involve. Participants were asked to contact the research team if they wished to take part in the study.

Those who expressed an interest were sent the questionnaire and returned it in a postage paid envelope. All aspects of the work were reviewed by the professional reference committee of the charity, and full ethical approval was granted by a University research ethics committee.

Data analysis

The overall aim of the analysis was to capture important features of the dataset in relation to the research focus, as represented by *patterned* responses³⁰ or themes. These themes were developed inductively and reflect what predominated across the entire dataset. Theme development followed the six phase process outlined by Braun and Clarke³⁰ (see table 3). The intention was to create an overall ‘story’ through which the meaning of the data in its entirety could be conveyed.

Table 3: Six phase process of analysis

Phase	Activity
1. Familiarisation	Reading of all questionnaires enabled a preliminary sense of the data to be developed. Subsequent verbatim transcription of responses to each of the five questions enabled a detailed appreciation of the (range of) content of responses, thereby enabling comparison both in relation to individual questions and the entire dataset.
2. Generating initial codes	Data were reviewed through repeated readings, allowing important features to be identified and relevant codes, capturing these features, to be assigned. Codes reflected what Braun and Clarke (2006:90) call ‘semantic content’, that is, the explicit or overt meaning of participants’ responses.
3. Search for themes	The relationship between all developed codes was considered via comparison of their content, looking for similarities and

	distinctions such that different codes could be brought together to form tentative themes and sub-themes. This process delivered a 'candidate' (Braun & Clarke, 2006:91) thematic framework.
4. Reviewing themes	The candidate framework was refined, involving a constant moving back and forth between established codes (and their attendant extracts of data) and the developing themes. At this stage, codes could be moved between themes, embryonic themes and sub-themes amended or discarded as a final set was developed. A concluding re-reading of the entire dataset ensured that these themes adequately 'accounted' for all data.
5. Defining and naming themes	Each of the identified themes was appropriately labelled and thereafter explained. Labels reflected the essential meaning and were the basis of a narrative that expounded the theme, making explicit what it addressed/captured, including through the use of relevant data extracts.
6. Producing the report (here, the Discussion)	The analysis was used to make empirically informed arguments concerning the collective implications of the themes for understanding the experiences of mothers caring for children with brain injuries.

Results

Five core themes were identified. Collectively, these themes reflect the key features and processes integral to caring for a child with brain injury, as these impact on mothers' mental health and emotional well-being. All quotes presented below are subject to minor grammatical editing to enhance readability and understanding. Information is provided in brackets after each quote concerning the study number assigned to the mother as well as severity of her child's brain injury.

Perpetually anxious

Mothers' described a ubiquitous anxiety inherent in caring for their child. This anxiety was related to several different aspects of the totality of caring. Firstly, because of the often quite significant changes in personality, especially those associated with unpredictability in behaviour, mothers ended up at best wary and, at worst, actually frightened by the possibilities of how their child might behave. As a result, they existed in a state of heightened 'anticipatory' anxiety, not to mention the distress experienced by witnessing and having to deal with any aggressive or otherwise disruptive behaviour.

"Since my son's accident his behaviour has changed a lot, he is not the same boy anymore. He is violent, he has hit me, marked me, he has had knives to me. He has had knives to his 14 year old brother". (10, Severe)

"My son is now like a Jekyll and Hyde character and is more angry and snaps at the smallest detail. He used to be so loving and so helpful, but has reverted back to a young lad again ...". (16, Mild)

"Unpredictable moods and behaviour as you never know when she will kick off, which makes it difficult to plan family events or outings". (34, Moderate)

As is clear from the above statements, an ingrained sense of foreboding characterised mothers' understandings of their child's potential behaviour that, in turn, encouraged social withdrawal.

Although this withdrawal was undertaken voluntarily, the context in which it occurred was manifestly not of the mothers' making. Rather, it was one in which they sought to protect their child as well as themselves (and wider family) from social embarrassment and censure in addition to concomitant hurt and humiliation. As suggested by the quotes, mothers saw themselves as having little choice but to withdraw because of how others understood and responded to their child's brain injury and behaviour.

Second, mothers' awareness of their child's particular vulnerability meant that they were continuously anxious about his or her well-being, irrespective of age. Their fears were all-encompassing in that they pertained to multiple aspects of their child's material, physical and emotional well-being. In significant ways, the process of physical maturity into adulthood only served to exacerbate parents' anxieties because of the juxtaposition between their child's physical age, and the legal and social independence this typically carried, and his or her 'real' cognitive capacity which fell (often far) short. However, whatever their child's age and associated disparity between expected and actual cognitive functioning and physical capability, parents' fears meant that, yet again, they remained constantly alert to and anxious about what might happen.

“Because of her age, legally adult age. ... control over her decision-making, seeing her do things which I feared would be worse for her e.g. returning to driving, not getting enough sleep ... while she was still passing out multiple times each day”. (20, Mild)

“My daughter’s life/situation/injury dominates my life as I worry about her constantly”.

(25, Severe)

“I worry about leaving [daughter] alone whether it is in the house or when she is out with friends. ... I always worry something will happen to her”. (28, Moderate)

These statements demonstrate how mothers were constantly fearful of what could happen, such that they went through the mental anguish of their child sustaining an injury or suffering in some other way, irrespective of actual occurrence. To the extent that mothers assume typically the role of primary caregiver, these fears are understandable, borne out of an awareness of their child’s vulnerability and their attendant need for protection. Their keen sense that they (alone) could provide this protection means that, despite the pressures 24/7 caring brings, mothers’ preference was to keep their child close by.

Third, mothers’ fears about their child’s welfare extended into some imagined, typically frightening, future. Given the lack of any conceptual ‘road map’ by which to anticipate a future state of affairs (unlike those of non brain-injured children) they were operating in the unknown. Accordingly, their anxieties were intensified. Furthermore, an awareness of their own progression towards old age and eventual death left mothers particularly fearful for their child’s welfare. Anxieties thus centred on a sense of their child being left ‘alone’ in the world, essentially bereft of the love and care they required.

“I fear of getting old and who will take care of her I think, of that every day”. (21, Severe)

“Trying to be positive about the future but deep down worried what the future holds for my child”. (32, Mild)

“My main feeling however is one of dread. ... I worry that after I am dead or unable to look after him he will be scared and lonely with no one who has his interests at heart to the same degree that I do (although I am sure his sisters will be there)”. (73, Moderate)

The above descriptions expose mothers’ deep-seated fears concerning both the contemporary and (imagined) future circumstances of their and their child’s lives. At least partly, these fears are based on awareness of the lack of/limitations in the care available from others, both formal and lay. This awareness included a strong urge to avoid ‘burdening’ other family members with a caring role. As such, mothers’ emotions were fraught between wanting their child to have the best possible care and knowing that for this to happen in their absence, the responsibility would fall to siblings. Being a mother to both left their loyalties (and their emotions) torn in different directions.

The guilty carer

Mothers’ statements revealed a painful guilt intrinsic to their relationship with their child, manifested in two quite distinct ways. Firstly, that associated with the pain and distress their child suffered, about which they were essentially powerless to do anything. Not only were they conscious of having failed to protect their child from the initial brain injury but, at times, saw themselves as responsible for inflicting suffering. Thus, although the provision of day-to-day

care (for example, feeding, changing dressings and administering medications) was entirely necessary, nonetheless, it placed on mothers the burden of ‘causing’ their child at best, discomfort and, at worst, considerable distress.

“He hates taking his medicine and will scream throughout wash-times despite attempts to calm him. He is very strong now and will fight ... often injuring me. I ... end up feeling exhausted and tearful”. (49, Severe)

“Sometimes I feel he looks to me to make things better for him and I find that unbearably painful that as his mother I could neither protect him from what happened nor can I restore him to full health and ability”. (45, Severe)

Second, mothers expressed an awareness of their child as ‘different’ and, as such, somehow ‘diminished’. Here, a muted sense of frustration was also articulated. It is significant that the statements made by mothers, particularly those that acknowledged exasperation with their child’s condition/behaviour, typically included reference to such feelings as unacceptable.

“Also having to constantly explain things, finding it hard to have a ‘normal’ conversation with her like I do with my other teenage daughters – and then I feel really guilty for saying that!”. (6, Severe)

“Attending to his daily needs such as making sure he gets up/goes to bed eats properly. Driving him places. It is frustrating that he is still so dependent on me as he is 16”. (55, Moderate)

Mothers’ statements thus revealed an extremely damaging circle of emotions involving love, commitment, exasperation, remorse and, finally, back to love and commitment only now with the added urgency of compensating for their ‘emotional betrayal’ of their child.

Finally, although infrequent, some accounts suggested a vaguely formulated regret that their child had survived the event or circumstances of their brain injury. This regret was never explicitly stated; rather, it emerged in muted statements that, if anything, sought to impress upon the reader their gratitude for the fact that their child, despite their injuries, remained alive.

However, it was the way in which these statements were framed, typically with reference to having to ‘work at’ being glad of their child’s survival, which implied an underlying reticence and/or regret.

“You constantly have to remind yourself how lucky you are that he is alive”. (39, Severity of brain injury unstated)

“People expect you to be grateful that your child is still alive. They want you to be a ‘saint’, consider it a gift & don’t want to listen to how hard it is”. (15, Severe)

“When I try to explain to family & friends the stress I am under I frequently am told I should count myself lucky that she is alive. I do...but because the injury is hidden no one understands”. (34, Moderate)

As the above quotes demonstrate, mothers embedded their distress and frustration in statements that, at face value, declared the precise opposite of the meaning which could be derived by ‘reading between the lines’. A clear demarcation between manifest and latent meaning thus enabled them to express (perhaps even ‘vent’) their regrets concerning personal life circumstances whilst continuing to stress their love and devotion as parents. The thematic label of ‘guilty carer’ thus captures the emotional turmoil experienced as mothers try to reconcile their private frustrations with the culturally endorsed values of unconditional motherhood. As such, it also calls attention to mothers’ awareness of the social pressures being exerted to continue to feel and respond to their child post-ABI as before.

The labour of caring

Mothers often alluded to the daily ‘grind’ of providing care to their child. At no stage were any explicit complaints made about having to provide this care. Rather, the statements revealed a profound weariness brought about by the drudgery inherent in caring, prompted by (often, many) years of day-to-day provision of care and with little or no prospect of an end in sight. As the following statements indicate, a tremendous commitment to caring for their child was juxtaposed with an awareness of being irrevocably tied to this role and the disillusionment and frustration this engendered.

“Being trapped, not being able to go out ... we’re stuck in most of the time, he needs help with every aspect of his daily life, I find it a constant chore doing his food, toileting, dressing etc.”. (80, Severe)

“That I could know [daughter] would be cared for if I was no longer here. I want to run away sometimes but I would never leave her by choice”. (26, Mild)

“The day to day trying to encourage him to eat, putting up with his mood & (sadness at times). The helping put on his splints & shoes, just the daily grind of helping & never seeing an end to it”. (24, Moderate)

The fact that much of the care was rather mechanical in nature contributed to the sense of drudgery, irrespective of mothers’ appreciation of its importance to their child’s ongoing survival. It would appear that the very monotony of caring meant that mothers could experience not only physical exhaustion but a mental ‘weariness’ brought about by the sheer repetitiveness of providing care. Moreover, their fatigue was exacerbated by the discord between having to do the same things over and over again but with limited ‘return’ in terms of manifest improvement in their child’s condition.

“[Son] has a difficult time remembering things and repeats himself all the time. Having to repeat myself 4/5 times before he understands or remembers is very tiring, and stressful”. (13, Moderate)

“I am often acting as a translator/mediator between him and the rest of the family, explaining what has been said and if necessary what is meant ... I find this very frustrating. ... Round and round it goes!”. (73, Moderate)

The daily grind of caring was compounded by other pressures, often associated with financial insecurity as well as perceived lack of practical and emotional support. Mothers regularly noted the material adversity they and their families faced. Typically, this adversity was related directly to restrictions placed on parents’ working/earning capacity, alongside the fact that their child’s physical and/or mental difficulties meant that they often required extra support in the form of, for example, paid assistance in caring or specialised equipment.

“Poverty even more stressful than brain damage e.g. ... benefits cut to lower rate, transport hell with no money. Adapted flat, can’t afford heating, white meter, can’t change supplier, can’t control it”. (12, Severe)

“If we were only given help, respite care etc it would be easy to keep going – I get terribly tired then I start to get depressed. As I’m a carer I’m only allowed to earn a little over £400 a month, this means I can’t work as much as I would like which is such a break from caring for a disabled child”. (24, Moderate)

Although mothers often referenced their relative social isolation and associated limited support from friends and family, by far the most keenly felt lack of support was that associated with professional/formal services. Attention was often drawn to the need to ‘battle’ for services, often

with little success. There was a sense in which the very act of seeking/securing support, something which should help parents to feel better, actually served to intensify their physical and emotional weariness.

“Fighting for everything exhausting. Social workers patronizing me over stupid things”.
(12, Severe)

“Although I have been to the doctors repeatedly and asked for help and social services but to no avail and yet when I don’t need the help they throw themselves at me ...”. (16, Mild)

“Really it has all been a battle”. (74, Moderate)

The above statements expose the additional labour that mothers were required to exert in pursuit of relevant services/effective care for their child and the detrimental outcome of their efforts. Most straightforwardly, the hard work (that is, the ‘battle’) involved in finding out about and subsequently attempting to secure such services/care served to increase the burden of caring. More fundamentally, it also served to deplete mothers of the very physical and emotional reserves that were so vital to their ability to care for both their child and themselves. Although the data was overwhelmingly indicative of the negative emotional impact of caring, there was limited evidence of more positive outcomes for some mothers. For example, one mother (60, Moderate) stated, “With all of the challenges set upon us from agencies that are meant to help I have become empowered and don’t take no for an answer,” thereby revealing a growing resourcefulness and strength of mind. However, no other participant responded in such terms

when answering any of the questions, suggesting that individual ‘empowerment’ as a consequence of having to battle for help, was not a common outcome.

A self-conscious apologist

Frequent mention was made by mothers of the need to explain and/or apologise for their child’s behaviour, based on an awareness of others’ perceptions of this behaviour as aberrant. In this context, mothers tended to highlight an incongruity between their child’s ‘normal’ physical appearance, which encouraged expectations of age-appropriate behaviour, and the actual behaviour he or she could display. Consequently, other people (sometimes including, most upsettingly, friends and family) had difficulty acknowledging the validity of their child’s behaviour.

“My son has severe brain damage but looks ‘normal’. People expect him to be intelligent when he is not. It is hard to keep explaining his situation”. (15, Severe)

“It has been stressful, for a while I didn’t go out or mix with people apart from my work. You feel as though no-one understands and because you can’t see the injury people just assume you’re making it up”. (64, Moderate)

“[I] wish school were more aware about ABI, feel they think child is ‘normal’ because she looks and acts ‘ok’ at school. Child is doing ok on paper but feels school is now a struggle and worries about it all the time”. (32, Mild)

These statements highlight the multiple stressors inherent in having to cope with, broadly speaking, the societal response to their child's brain injury and associated behaviour. That is, coping is undertaken in a largely threatening social environment, one in which lack of understanding and support from others is manifest. Mothers' resultant sense of injustice, frustration and distress is evident. Furthermore, there is a strong suggestion of social withdrawal as they seek, simultaneously, to avoid embarrassment and protect their child from the unfair character assassination of others.

Perpetually grieving

Mothers expressed a sense of profound loss, as well as enduring grief or mourning occasioned by this loss. Two distinct aspects were discernible. Firstly, that relating to 'loss for self' and, second, that relating to 'loss for child'. In relation to 'loss for self', mothers' referenced two separate, but related, processes. Firstly, a sense of personal loss in respect of, for example, career opportunities, social life and wider family life. Accordingly, it was difficult, if not impossible, for them to detect an area of their lives in which some personal diminishment had not occurred.

"I'm terrified. Will I be a bag lady? My personal relationships have suffered e.g. divorced, don't have enough of me to go round. I've let myself go. ... Feel like I don't fit in (excluded) from normal life ...". (12, Severe)

"... our perfectly planned family unit got blown apart. My son who we adored deeply ... had to go and stay with a fantastic family friend for months on end. (My relationship with him has suffered tremendously). ... It's very difficult to know just what piece of you to give

to who at times like this. And all the time yourself just keeps going further down the list for caring about”. (63, Severe)

The crushing sense of loss and consequent ‘grieving’ occasioned by this loss is palpable in the statements quoted above. Although accepting of the need to prioritise their child’s requirements, the consequences, including in relation to the relative neglect of other children, appear profoundly damaging to mothers’ sense of their lives as rewarding or successful in any sphere except for that relating to caring for their child.

Second, mothers described their loss of the child they had parented prior to his/her brain injury. Here, descriptions depict a state of chronic mourning for someone who had existed/prospered in the past and who they had envisaged prospering in the future. As is the case with all of the statements made by mothers concerning any negative thoughts or feelings, acknowledgement of their child as different from, or less than they were before their brain injury, was implied (rather than explicitly articulated). Thus, mothers used words such as ‘different’, alongside those such as ‘mourning’, ‘struggle’, ‘hard’ and ‘heartbreaking’, thereby establishing a negative association between the before and after circumstances of their and their child’s lives.

“Nearly losing a child and then to have them back but ‘replaced’ by another child can be very depressing. People say how lucky we are but we still have in fact lost a child and still grieve and want and miss the child before ABI”. (4, Severe)

“I sometimes think I can never truly be happy again. I keep busy, I’ve tried to make my son the best he can be ... But I always feel sad, when I think of the child he could have been ...”. (24, Moderate)

“I can’t imagine going through anything worse, even death there’s an end. This goes on day after day forever and I lost my son ...”. (36, Severe)

These statements draw attention to the perpetuality, even intensification, of mothers’ grieving as they watch their child mature in ways profoundly different from those imagined. Year-after-year they are reminded of the loss of their child (and his/her potential). The all-encompassing sense of loss experienced by mothers was further highlighted as they outlined their awareness of loss, this time sustained by their child. This second dimension of grieving (‘loss for child’) demonstrates how mothers grieved intensely on behalf of their brain injured child concerning his/her loss of their potential life-course.

“Grieve constantly for what she’s lost – career, marriage, family”. (75, Severe)

“Sadness for what might have been his future. I still struggle with the fact that he’s on a different pathway now (albeit a relatively great one) ...”. (62, Moderate)

“The main impact for me has been so broken hearted at what [son] has lost in life”. (71, Severe)

These statements highlight the impossibility of emotional respite as the lives of mothers, alongside their children with brain injury, unfold over time. In practical terms, they are required to make ongoing adjustments to their own and their wider family's lives, often radical and with adverse personal consequences. This adjustment is achieved against a backdrop of being constantly reminded that their child will never be the person they might otherwise have been. No matter what adjustments (sacrifices), no matter how hard they and their child strive, that (potential) person is gone. The emotional devastation wrought by the totality of their and their child's loss is clear.

Discussion

The burden of caring: collective and enduring over time

Findings provide valuable detail concerning the multifaceted and perpetual nature of the burden of caring. This burden stems from, amongst others: having to watch their child deal, day-to-day, with, at best, challenging circumstances; dealing with the unpredictability of their child's behaviour; grieving over their child's (and their own) lost life potential; coping with the negative reaction from others, including friends and family; tending to the physical and cognitive needs of their child; having to manage ongoing adaptation and coping in response to their child's changing needs over time and, underpinning all other emotional turmoil, dealing with the contradictory emotions of love, frustration, resentment and guilt.

As we have shown, these experiences run concurrently and repeatedly over time. The bulk of research has tended to separate out and, in the process, to *isolate* issues relevant to parents' caring experiences²⁸. Although useful in providing insight into important enablers and barriers,

this literature is of limited value in helping to understand the nature and impact of caring over time because of its tendency to conceptualise relevant issues as temporally and causally independent of one another. Our findings provide a more nuanced understanding, showing how the ongoing, multiple and varying dimensions of burden *collect* together as they operate over time. Experience of one, or even some, of these dimensions would, of course, place significant pressure on mothers' mental well-being. The fact that the burden of caring is not only multi-dimensional but follows the parent throughout the entirety of their and their child's life is particularly injurious.

In the context of this enduring burden, the data reflect ongoing physical and emotional vulnerability as mothers continued to care over time, typically in the context of, at best, limited professional/lay support. There was little sense of successful psychological adjustment to their child's brain-injury and ongoing circumstances. Day-by-day mothers faced a wide range of challenges associated with (caring for) their child's condition. Moreover, they had to witness, time after time, instances of their child's lost life potential. We found only one statement explicitly reflecting a growing (sense of) emotional robustness in dealing with issues arising from their child's condition. Accordingly, our findings directly challenge the idea that caregiver burden can level off/decrease as adjustment to/accommodation of the brain-injured person's condition is made ¹¹. Although mothers described a range of 'successes' concerning their child's development, achievements, care and future, none of these were either explicitly or implicitly associated with diminution in perceived burden. Boschen, Gargaro, Gan, Gerber, and Brandys ³² talk about children with ABI 'growing into' their disabilities as they fall increasingly further

behind their peers. Our findings suggest an associated intensification of mothers' care giving burden as this growing occurs.

Findings call attention to mothers' *enduring* sense of loss - of the child before injury - and of, again, enduring grief for this loss. Although this grieving includes that concerning their own and wider family's lost life opportunities, it is most keenly felt with regard to their child. Mothers' emotions are complicated and contradictory; at the risk of over-simplification, on the one hand, grateful for their child's survival and, on the other, anguishing over the loss of the child they knew before and imagined in the future³³. Because of these contradictory feelings, mothers' relationships with their child were emotionally fraught. Relatively straightforward tensions between, for example, wanting to protect their child and encouraging independence co-existed with those much more emotionally destructive, particularly the frustration, resentment and accompanying guilt that built up over years of caring (see also Kao & Stuifbergen,²⁷).

The exacerbating impact of social and cultural context

The issues discussed above are inextricably bound up with one that directly informs *all* mothers' experiences and consequent emotional well-being, namely, the socio-cultural context in which caring for a brain-injured child occurs. The impact of this context on a wide range of experiences related to (perceived) physical and mental well-being has been demonstrated in other areas (see, for example, Peake, Manderson and Potts³⁴; Scott³⁵). However, it has received only limited and recent attention in the brain injury literature and has tended to remain implicit in analyses.

Our findings underscore the value of such a perspective as they demonstrate mothers' experiences of caring for their child to be profoundly constrained by a range of socio-cultural processes. Two main aspects are here discussed. Firstly, in relation to their understanding of, and response to, their child's development over time. As has been shown, to a greater or lesser degree, mothers acknowledged developmental deficits, reflected in descriptions of their child's achievements compared to those of other non-brain injured children and/or what they had expected or envisaged for him/her. Here, mothers are drawing on dominant cultural expectations that uphold movement through specific physiological, cognitive *and* social achievements/stages during normative life-cycle development³³. In so doing, it is difficult for them to conceive of their child's development in essentially positive terms, irrespective of their appreciation of individual progress/improvement.

Their experiences fall broadly in line with DeMarle and Le Roux's³⁶ argument, which asserts that families of physically and/or mentally disabled children experience a painful 'discontinuity' between what they have come to know as 'normal' (for example, being able to watch their children grow into independent adults) and what they personally experience in terms of their brain-injured child's development. At the root of this disparity and concomitant distress lies the absence of cultural norms that specifically value brain-injured individuals and uphold the merits of their specific personal development. Mothers are thus restricted in their ability to come to terms with their child's brain injury and development over time because, no matter how much individual progress *they* recognise and celebrate, this is not shared. Mothers are constantly reminded (through the response of others) that their child and his/her achievements remain, at best, unacknowledged or undervalued and, at worst, disparaged within society generally.

Moreover, because their child is socially and culturally marginalised, opportunities to realise his/her full potential are severely compromised. And, of course, mothers' awareness of this relative exclusion only adds to their anxiety and sense of foreboding as their child ages.

Second, in relation to mothers' experiences of loss, our findings clearly demonstrate a profound sense of loss and attendant, ongoing grief. Other work has demonstrated a similar experience of *chronic* grief over parents' loss of a child they "knew in the past and imagined in the future"³³ (p.1502). However, as our mothers were well aware, such mourning was considered inappropriate, even unacceptable. Quite simply, their loss (of the child they had before brain injury) was not socially acknowledged or culturally upheld. Not only were they expected to celebrate the survival of their brain-injured child, but also were prohibited from expressing any degree of frustration or regret concerning the impact of this survival on the child or themselves and wider family. To do so would, of course, have challenged accepted norms concerning the all-encompassing and unconditional nature of motherhood. Awareness of such cultural mores lies at the root of mother's statements concerning the 'guilt' they felt when expressing any kind of negative feelings concerning their brain-injured child. So strong are the cultural values concerning normative mother-child bonds that the mothers in our study self-imposed limitations of what they felt they could 'reasonably' express.

Given that the grief mothers felt at the loss of the child before brain injury was not culturally approved it could find little or no outlet, its focus and content being so far removed from that which is culturally endorsed, that is, grief occasioned by loss through death. The pressure thus exerted to conform to cultural expectations only served to heighten emotional distress as mothers

were denied opportunities to grieve and thus to come to terms with their loss, their ‘new’ child’s brain injury and attendant changes in personality/behaviour. Contrary to Rycroft and Perlesz ³⁷, who argue that non-finite loss is not validated either culturally *or* by individual mourners, our mothers were acutely aware of a real loss and mourned this. However, it was the public *expression* of their appreciation of loss that they experienced as prohibited and, therefore, could/would not acknowledge to others.

Strengths and limitations

Participants were obtained via convenience sampling. Such a sample may be skewed due to the self-selected nature of participant engagement; those willing to participate may have had experiences of caring that impacted on their understandings and mental health in particular ways. The findings are self-report, regularly associated with problems of validity ³⁸. However, the importance of enabling subjective perspective remains, particularly when the topic under investigation is sensitive, as is the case with mothers talking about their emotional well-being in the context of parenting a child with brain injury ³⁹.

A major strength of the study is the data obtained reflecting collective caring experiences and attendant impact on emotional well-being over time. Mothers were encouraged to reflect (back) on their experiences in their totality. Taken overall, this data reflect generalised sorrow, frustration and anxiety. This is not to say that mothers did not describe more positive aspects to their and their child’s lives. They did; descriptions encompassed examples of individual triumph over adversity, acknowledgement of progress in their child’s condition as well as (limited)

optimism about their child's future. However, such descriptions were relatively infrequent and certainly did not coalesce around an analytically identifiable theme.

Conclusion

Our study is one of the very few that has sought to unpack the reasons underpinning the emotional well-being of mothers' caring for a child with brain injury. In so doing, it highlights the collective and inter-dependent nature of the issues, challenges and pressures mothers face. In that a finely grained insight was achieved, it is clear that the experiences of mothers of children with reported severe, moderate *and* mild brain injury share many facets. An important reason for the correspondence in experience is shared socio-cultural context. All mothers were subject to the same socially derived limitations concerning healthcare professional, wider welfare system and lay support. All were subject to the same cultural pressures to understand their child's brain injury and undertake his or her care according to specific values. In essential respects, it was not the brain injury that impacted so adversely on mothers' emotional well-being but lack of understanding, at both an individual and societal level.

This lack of understanding (and concomitant sense of isolation) as it 'builds up' in a mother's life over time, is of particular value in suggesting an important element of appropriate support. As our study data demonstrates, lack of understanding is, in essential respects, grounded in wider cultural notions surrounding (caring for someone with a) brain injury. Consequently, the value of creating 'communities' of shared experience and knowledge seems pertinent for two important reasons. Firstly, it allows for the development of support that is relatively immediate, responsive and flexible. Second, it brings together peers with similar life experiences. Such similarity is the

basis of empathy and sharing of burden within an alternative (to the encompassing) culture of understanding of and response to (caring for someone with) brain injury.

Surprisingly little empirical research investigating group / peer support within a brain injury context has been undertaken to date. Extant findings overwhelmingly confirm our thinking. In a relatively early study, Hibbard et al.⁴⁰ demonstrated positive outcomes for participants, including increased knowledge of TBI, enhanced overall quality of life, improved general outlook and ability to cope with depression. Similarly, Gan et al.¹⁹ highlighted how caregivers valued the opportunities for “venting” and having someone to listen to them as this confirmed they were amongst others coping with similar issues. In their evaluation of a multiple family groups intervention, both Charles et al.²¹ and Huntley and Perlesz⁴¹ highlighted a range of positive outcomes, including a reduction in personal stress, anger, depressive symptoms, shame and isolation alongside improvements in coping skills. In a detailed analysis of families’ reflections on their experience of a ‘family-to-family’ link up programme, Butera-Prinzi et al.¹³ identified the multiple benefits of the peer support provided, including: relief from realising that others share similar experiences, the value of sharing emotions, the importance of experiencing non-judgemental attitudes, the sense of empowerment and hope gained and the building of a sense of community through the development of relationships over time.

The comprehensive benefits identified across these studies are entirely understandable given the experiences documented by our study. As carers of a child with brain injury, mothers were both socially and emotionally marginalised, with profound consequences for their personal well-

being. In that a sharing of collective experience can serve to counter such marginalisation, peer support can act as an important adjunct to that provided professionally.

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